**What are the factors that facilitate or hinder resilience in older Spousal Dementia Carers? A qualitative study.**

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Abstract

**Objectives:** Much is known about the factors making caring for a spouse with dementia burdensome. However, relatively little is known about factors that help some spouses become resilient. We define resilience as ‘the process of negotiating, managing and adapting to significant sources of stress or trauma’ (Windle & Bennett, 2012, p. 219). We aimed to assess whether spousal dementia carers can achieve resilience and to highlight which assets and resources they draw on to facilitate or hinder resilience, using an ecological framework (Windle & Bennett, 2011).

**Methods:** 20 in-depth qualitative interviews with spousal carers from two carer support groups and a care home in North West England.

**Results:** Eight participants were resilient and twelve were not. A resilient carer was characterised as someone who stays positive and actively maintained their relationship and loved one’s former self. Resilient carers were knowledgeable and well-supported by family but especially friends, with whom they shared this knowledge. They were more actively engaged with services such as respite care.

**Conclusion:** There is a need to move towards more ecological models of resilience. We propose that access to assets and resources is not always sufficient to facilitate resilience. Implications of these findings are discussed.

**Key words:** resilience; dementia; spousal care; ecological framework.

Introduction

Caring for a person with dementia is uniquely stressful (Lévesque, Ducharme & Lachance, 1999). This burden often falls on family carers. Approximately 27% of primary carers in the UK are spouses (Alzheimer’s Society, 2011). Pinquart and Sörensen (2003) reviewed over 400 empirical studies on caregiving and noted that the majority centred on burden. However, caregiving burden is not the full story. Whilst it is true that stress, at least initially, is common to all who face adversity, carers are not a homogeneous group (Bonanno, 2004). Some spouses might find caring entirely burdensome whilst others might find it life-enhancing; these carers may be resilient (Windle & Bennett, 2011).

Resilience is commonly examined from a psychological perspective, with recent papers emphasizing psychological resilience and the role of a resilient personality (Windle, Woods & Markland, 2010). More recently, qualitative work has emphasized the link between psychological resilience and community and social aspects of resilience (Wiles, Wild, Kerse & Allen, 2012,). This is important since individuals may fail to become resilient if the community does not facilitate opportunities to adapt (Ungar, 2011). Despite this resilience is often narrowly defined and not well operationalised (Gaugler, Kane & Newcomer, 2007; O’Rourke et al., 2010). In light of these limitations, Windle (2011) defined resilience thus: “The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or ‘bouncing back’ in the face of adversity” (Windle, 2011; p. 163). Bennett (2010) operationalised resilience using a number of criteria: participants must view their current life positively; be actively participating in life; return to or maintain a life that has meaning or satisfaction; be coping and not be distressed. There is still a need for an integrated and fully operationalised definition of resilience, which may be used to determine resilience in carers. In this paper we draw upon both of these accounts to provide the following criteria for resilience (see Bennett, Reyes-Rodriguez, Altamar & Soulsby, submitted). First, there must be a significant challenge, and here this is caregiving; there must be no obvious sign of (di)stress; maintenance of a life of meaning and satisfaction (a sign of bouncing back); active participation in life (a sign of managing); and current life must be seen as positive (a sign of adaptation). Our conceptualisation allows us to address whether resilience can be achieved in our participants, and for the facilitating/hindering factors to be more easily identified and characterised in the third stage of analysis.

These criteria are illustrated in the literature. Studies have shown that carers with higher perceived control and who favour challenge over stability present with less depressive symptoms at one-year follow-up (O’Rourke et al., 2010). Gaugler et al. (2007) found high levels of resilience in dementia carers, operationalised as low perceived burden with high care demands, led to significantly less instances of institutionalisation at three-year follow-up. They characterised these resilient carers as more accepting of formal and informal support. However, the type of support is important; support may be detrimental if it creates feelings of over-dependence (Ingersoll-Dayton, Morgan & Antonucci, 1997) or if it is not empathic (Haley, Levine, Brown & Bartolucci, 1987). Carers may prefer and compare themselves with those in a similar situation (Farran, Loukissa, Perraud & Paun, 2004). Formal support and service provision are equally important. Support services designed to provide practical support to encourage carers to remain socially active and maintain healthy living are highly valued by those carers with access to them (Seddon et al., 2009). Resilience, therefore, can be fostered within the individual, their immediate surroundings and wider social environment.

Windle and Bennett (2011) developed a theoretical model of resilience applied to carers (see Figure 1). The model posits that each carer draws on individual assets. The framework emphasises the fact that carers do not exist in isolation but interact with their environment by drawing on community and societal resources. Carers use these assets and resources to either facilitate or hinder resilience. The absence of assets and resources may lead to compromised wellbeing or further caring challenges. No qualitative work has been conducted with carers to examine which factors are associated with resilient and non-resilient carers, nor whether qualitative themes can be mapped on to the framework.

Figure 1 about here

The current study uses a qualitative approach to examine the capacity of spousal dementia carers to be resilient. We use the criteria outlined above to classify our participants as either resilient or not resilient. We will highlight the facilitating and hindering factors that participants draw on to achieve resilience, and examine whether they map on to the resilience framework (Windle & Bennett, 2011). The primary research question asks, can spousal dementia carers achieve resilience? The first objective aims to address which assets and resources the carers draw on that facilitate or hinder resilience. The second objective aims to address, how easily these assets and resources map on to the resilience framework?

Method

*Participants*

We recruited from two dementia support groups and a care home in NW England. The first author made contact with staff at each of the organisations by phone, before being invited to give a brief talk about the research and to provide information. Although thirty-five carers volunteered to take part in the study, this paper focuses on the twenty participants who provide spousal care. This exceeds the minimum theme saturation threshold of twelve interviews; the point at which no new information or themes are observed in qualitative data (Guest, Bunce & Johnson, 2006). There were thirteen women and seven men. Each had been caring for their spouse for between 2 and 10 years (mean = 5.62 ± 2.73) and had been married for between 28 and 61 years (mean = 50.35 ± 7.36). Age ranged from 62 to 86 (mean = 75.95 ± 7.47). Most participants lived with and cared for their spouse at home although two were already widowed (Mrs L., Mr Gr.) and another had admitted her husband into nursing home care (Mrs G.). Care recipients had different levels of impairment and care durations did not always correspond with the exact time of diagnosis. For example, Mrs F. had provided eight years of care to her husband, but he only had a formal diagnosis of dementia for three years. The socio-economic status distribution of the participants was broadly representative of similar demographics in the British population (Office for National Statistics, 2011). See Table 1 for demographic details.

*The Interview*

Semi-structured interviews were conducted and digitally recorded during monthly carer meetings. Interviews were conducted by the first author and by two research assistants, LW and NH. Participants were taken to a private room where the interview took place. Interviews each lasted for between 25 minutes to one hour. The interview started with factual questions (Section A) to acquire age, marriage, care duration and employment history. We used an open chronological and retrospective approach to allow feelings and events to be traced to specific stages within the care duration. Section B asked about life before the presentation of cognitive impairment in the care recipient. Participants described a typical day spent alone and with their spouse, relationship quality, division of responsibility and type and amount of support given and received. Participants were asked about the period surrounding diagnosis or first suspicions of impairment (Section C): specifically, their initial emotional and behavioural reactions to the news. The final section (Section D) concerned the present time, asking the same questions as section B in light of current circumstances. We asked concluding questions that prompted participants to consider which of their own personal characteristics may have helped them as a carer. They were given the opportunity to provide advice and recommendations for formal practice and legislation. The study received ethical approval from the University of Liverpool Research Governance Committee, and all identifying features have been anonymised in the quotations used.

*Method of Analysis*

We used a three-stage hybrid method in our analysis of the data (see Bennett, 2010). We used a grounded theory approach (Bennett & Vidal-Hall, 2000; Charmaz, 1995; Smith, 1995) as an exploratory method to read and code the interviews. We adopted this method without the intention to develop a theory and without any apriori assumptions about the data. The remaining analysis then departed from the principles of classical grounded theory in order to identify resilience in our sample, and determine which factors determine resilience using the ecological framework (Windle & Bennett, 2011):

1. The first author read through each interview in its entirety to gain a contextualised understanding of the experiences of each participant. The first author then coded the interview on a line-by-line basis and grouped these codes into focused codes, before developing themes based on all of the interviews. The first author followed a reflexive approach so that each new and emergent theme led to re-coding. All interviews were then coded blind by the second author. The two authors then discussed the coding and a consensus was reached. Some prominent themes to emerge at this stage were: resilience, staying positive, knowledge and expertise on dementia, and the importance of shared experience.
2. Next, we re-read the interviews in order to identify our participants as resilient or not resilient. Each author classified each participant independently, using the same method as above. We used the criteria outlined earlier:
3. There must be a significant challenge: caregiving.
4. No sign of (di)stress.
5. Maintaining a life of meaning and satisfaction (a sign of bouncing back).
6. Actively participating in life (a sign of managing).
7. Current life seen as positive (a sign of adaptation).

Finally, we re-examined the codes from stage one in order to identify the factors that facilitate or hinder the capacity for resilience as identified at stage two. We specifically addressed two research objectives: We identified which individual assets and community and societal resources participants drew on to facilitate or hinder their capacity for resilience, and whether or not they could be mapped onto the resilience framework. By classifying our participants first, using an independent set of criteria (Bennett, 2010), we avoided circularity in the findings.

Analysis

*Classification*

Our primary research question was: can spousal carers achieve resilience? We identify eight participants as resilient and twelve participants as not resilient. Thus, some spousal dementia carers can achieve resilience. The following stages of analysis will determine the multidimensional nature of resilience; for example, some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience. Resilient participants are younger (mean = 73 years ± 4.81) than non- resilient participants (mean = 78 years ± 8.58). Resilient participants have been caregiving for longer (mean = 7 years ± 2.77) than non-resilient participants (mean = 4 years ± 2.06). A greater proportion of men are resilient (5/8), whereas a greater proportion of women are not resilient (10/12) (see Table 1). The following qualitative data illustrates how participants are classified as resilient or not resilient:

Mrs C. is classified as resilient because she shows no obvious signs of distress. She has adapted to becoming a dementia carer and views her current life positively as she adopts a positive outlook from the point of diagnosis and continues to instil this in her husband:

It changed and yet I tried to be positive and say all they’ve done is give it a name. You’re still the same person you were yesterday. (Mrs C., P7, L7)

She ensures that both her and her husband maintain a life that has meaning and satisfaction by continuing to travel on holiday and engage with the local community. She has bounced back from the initial challenge of becoming a carer:

We’ve been very lucky. We travelled before he got Alzheimer’s and we continued to travel with Alzheimer’s up until two years ago when it got too difficult. We realised all the things we wanted to do in retirement so we didn’t let it stop us. (Mrs C., P3, L7)

Finally, Mrs C. actively participates in life through managing charity work and by attending support groups:

I’ve got to go out every day. He’s at an allotment this morning ran by [charity]. That’s a charity I’ve accessed an awful lot, they’ve been invaluable. (Mrs C., P17, L13)

Conversely, Mrs W. is classified as not resilient because she is distressed; she is not positive about her current life and seems resigned to her circumstances:

This is my retirement in other words. Not what I planned of course but there you go. (Mrs W., P2, L12)

Mrs W. has not managed to bounce back as she focuses mainly on those things that have become lost or changed irreparably, rather than maintaining existing competencies:

It’s not husband-wife anymore it’s carer-caree… It’s like looking after a child. (Mrs W., P17, L1)

Although Mrs W. participates in a carer support group, she does not welcome social support from her family and so does not fully participate in life:

I do have a problem with family support because we don’t get many phone calls from his lot. We don’t encourage them to come up to be honest because he doesn’t like visitors, well it’s not that he doesn’t like people, he loves people. (Mrs W., P8, L18)

Table 1 about here

*Mapping resilience factors on to the resilience framework*

Our research objectives addressed; i) which assets and resources carers draw on that facilitate or hinder resilience, and ii) how these might map on to the resilience framework. Although the process of analysis happened sequentially (see Method), we integrate these questions by addressing each factor and mapping it under the relevant level of the resilience framework.

*Individual level of the resilience framework*

*Psychological assets*

The first theme that facilitates resilience is maintaining continuity. Whereas all participants emphasise the decline in function of the care recipient, some participants maintain and encourage aspects of their spouse’s former self. Mrs Wi. actively encourages aspects of her husband’s former lifestyle:

He used to go out every Monday and every Friday playing snooker and that hasn’t stopped. He goes on his own because I’ve told them right from the beginning about [husband] having Alzheimer’s. (Mrs Wi., P13, L14; not resilient)

The maintenance of self-identity and existing competencies reemphasises the fact that resilience may not just concern adjustment and change, but may concern the management of stress and maintenance of normal functioning. Here, we show that carers do not flourish or become ‘super functioning’, they maintain previous functioning by actively emphasizing features of their previous life. Another facilitating theme is the ability to stay positive:

I’m positive. I laugh and I sing and she laughs and I act soft in the house. I’ve even said to one of the neighbours about my singing and she says [Mr Go.] it’s a good job we’ve got a detached house. I sing at the top of my voice. (Mr Go., P17, L17; resilient)

Humour is an important asset in facilitating dementia caregiving and mutually enriching for carer and care recipient alike. Participants also frequently use downward comparison when referring to other care recipients or carers:

I was getting a little bit depressed and then I have a talk to myself and I think, you know, there’s millions of people like these and in one respect he’s been lucky if he’s going to have it that he got it when he was eighty and not fifty. (Mrs S., P17, L8; not resilient).

The use of downward comparison facilitates resilience by diverting attention from the challenge of caregiving and providing meaning so that, given the wider context, carers are more appreciative of their own circumstances which become normalised. In contrast, some participants take a more negative outlook of their experiences which hinders resilience. These participants are typically less resilient:

If there is a problem that’s weighing you down a bit you just work at it, don’t you? That’s your life. You’ve had the best and now you’ve got to put up with the worst. (Mr Gr., P15, L22; not resilient)

The most resilient participants do not simply stay positive in spite of burden; they use caregiving as an opportunity to acquire information and expertise on dementia. Whilst the propensity to acquire knowledge is an individual psychological asset, it requires the carer to interact with the community and use wider societal resources:

I went on the internet, got up what medication he should be on… and I was like a dog with a bone basically. We just became proactive. Within a couple of weeks I went to the Alzheimer’s [support centre] and I just sort of took on board everything but, it’s nine years later and you’re still learning all the time. (Mrs C., P11, L8; resilient)

Psychological assets seem to be dominant in our sample. Psychological assets interact with community and societal resources, as Mrs C. highlights. One might suggest that attempts made to promote resilience should start with individual psychological assets, as it is Mrs C’s drive to acquire knowledge that leads her to interact with wider services.

*Material resources*

Most of the sample report having sufficient finances to support their role but having access to disposable income facilitates resilience by leading to a better quality of life for the carer and care recipient alike:

We had a lovely life. Ups and downs like everybody else…We’ve been very lucky. We travelled before he got Alzheimer’s and we continued to travel with Alzheimer’s (Mrs C., P3, L5; resilient).

For other participants, access to disposable income is not always useful and sometimes hinders resilience, as Mr Ha. explains:

We’re spending no money. We have a system at the bank where it clears it down to two thousand for the rest of the month and the rest it clears away. I could well afford to buy anything I just can’t think what to buy. (Mr Ha., P8, L12; resilient)

Specifically, access to material resources may not necessarily equip someone to be resilient. Although Mrs La. claims to have had a very good life, going on cruises and on ‘wonderful dancing holidays’ (P2, L16) with her husband prior to his dementia, she now feels differently:

I feel I’m a prisoner. It’s a prison sentence for me and for him because you’ve lost the freedom we had before. (Mrs La., P8, L35; not resilient)

*Community level*

*Family relations*

Although most participants value the support they receive from family members, many prefer it if family support is ‘hands off’ rather than over-involved, and reserved for practical rather than emotional support. This theme is characteristic of even the most resilient of participants, as Mrs C. describes when referring to her two adult daughters:

We said you’ve got your own children now all in school, your husbands with jobs. We will get help from other people. We will find help as and when we need it. (Mrs C., P13, L5; resilient)

Other participants hold stronger views on the role of family support. Although Mr Ha. acknowledges that his daughter has been present and sympathetic, he goes on to say:

Our daughter has been coming over Sunday afternoon regularly lately. I don’t really want her to, it’s my place. (Mr Ha, P7, L36; resilient)

Although resilient, Mr Ha. is generally dismissive of support whereas Mrs C. appreciates the importance of support. Carers may prefer it if they control the amount of family support they receive to maintain independence and avoid feelings of over-dependence.

*Social support*

A great source of social support comes from the friends of participants, particularly from friends in similar circumstances. Social support facilitates resilience most when participants are able to demonstrate and share their expertise and insight with others. This is illustrated by two interviews with participants who are friends through a support group; Mrs C. advises Mrs Wi. with regards to a specific problem:

One of the girls…Her husband got a strop on this morning because he kept asking her the time and she was saying five to ten five to ten and she said it’s because you’re deaf. She said he got so angry and stormed upstairs and I said oh, cause we don’t mind telling each other stuff, two things there, I said one; you’re pointing out another failing which makes him feel bad, and the other thing is; you need to look at does he know what five to ten means. (Mrs C., P22, L21; resilient)

When I got in [Mrs C.] said well he might not be recognising what five to ten is and I said oh, you see you learn something every day and you think you’re down but knowing that somebody else has got another look on it. (Mrs Wi., P22, L17; not resilient)

This highly-specialised and confident application of knowledge highlights that dementia carers can become experts on the condition as well as their care duties. The receipt of advice can be as important as the provision of advice. Resilience might predispose individuals to take control of the role, garner information and become experts; this knowledge can then be passed on to others in the same situation. Sharing advice reminds us that each carer is embedded within a wider social arena.

This type of stable and supportive friendship is less common in non-resilient participants:

People drop out, you know, friends. They don’t fall out with you but you can tell they’re not in. There’s nothing for them anymore. You’ve got no conversation and they’ve got their own lives and their own friends and that’s a bit hard. So you are a bit isolated. (Mrs H., P4, L20; not resilient)

This category represents an interaction between each level of the resilience framework. Mrs C. and Mrs Wi. met in the support group, a societal resource, before sharing individual resources on a community-level.

*Social participation and cohesion*

Many participants emphasise the social groups they are part of, and the function they serve. Participating in social groups facilitates resilience:

I’m in an international Christian group which is good because not only do you have spiritual direction but you have the group supporting you. And whatever you say is confidential, they don’t repeat it anywhere else. They come out with whatever’s hurting them and you’re there to listen and they do the same for you. (Mrs La., P7, L19; not resilient)

Some of the more-well supported participants emphasise the value and function of the dementia support groups in particular. The friends made here are a more highly regarded source of social support by all who have them, as Mrs Go. explains:

Coming here [support group] has helped me because the people that come here are in the same position as I am. They’ve been in it longer than me some of them so I can use their experience and I can relate to what they’re saying. (Mrs Go., P22, L4; resilient)

For some non-resilient participants, attending groups is the only form of social support they have access to:

I don’t think there is anybody apart from going the coffee mornings. Obviously my daughter is distressed so I couldn’t really put it on her. (Mrs Cl., P9, L24; not resilient)

Dementia support groups facilitate resilience by providing a forum to acquire and share information by using the expertise of other carers in similar situations. Support group friendships provide a great source of practical and emotional reassurance.

*Social resources*

*Health and social care*

Participants make use of many different health and social care services, including day care, home help, support groups and respite care. Resilient participants are more likely to acknowledge their own limitations and know when to take a break. Eight out of twenty participants in our sample refer to some form of respite care and four of them use it. Those who use respite are classified as more resilient than those who do not so it represents an important facilitator of resilience:

I’m getting respite on a weekend. I really do know the meaning of recharging my batteries now. I feel more… on the Monday morning right let’s get on with the day. (Mrs C., P13, L22; resilient)

Some participants like the idea of respite care but do not know that it is available to them:

If carers could get respite care on a regular basis that’d be a most wonderful thing because it would give them the strength to go on, wouldn’t it? Rejuvenate them. (Mrs La., P11, L19; not resilient)

By reducing or temporarily removing the objective burden caused by the care recipient, the participant has an opportunity to ‘recharge’ some of the individual assets of resilience. Although respite care facilitates resilience for both carer and care recipient, not all participants draw upon it. It is our non-resilient participants who are least likely to use this service; either they are unaware of the service; do not know how to acquire it; or feel that they are not ready for it.

*Other services*

Some participants take part in unique innovative services which facilitate resilience:

We helped make a DVD for [local health service]. They interviewed the two of us together…His theme song for that is always look on the bright side of life [laughs]; the Monty Python one. (Mrs C., P9, L17; resilient)

Mrs Wi. spoke of a pilot scheme that she is part of at the local memory clinic:

I do voluntary work as well…I’m a carer talking to the carers…they ask the questions and I say and that’s where I learnt about that…I know it sounds daft but it is a break away, it’s different, and yet you’re helping others. (Mrs Wi., P18, L21; not resilient)

These services are quite different from the latter health and social care services in that the participants seem more engaged with them. Carers may be more likely to use societal resources if they can provide social support to others in the same situation. Services which encourage independence and ‘giving back’ rather than dependence may be preferred. This interplay represents an interaction between societal resources and community resources in the resilience framework.

Discussion

Our primary research question asked whether spousal dementia carers could achieve resilience. We have shown that some can achieve resilience, although the full picture is more complex. Our research objectives were to identify the assets and resources carers draw on that facilitate or hinder resilience, and to address how these might map on to the resilience framework (Windle & Bennett, 2011). We identified a number of factors that facilitate or hinder resilience in spousal dementia carers and found that these map well on to each level of the assets and resources in the framework.

Facilitating factors emerged primarily at an individual level, and included mainly psychological assets which were frequently associated with resilient participants. For example, maintaining continuity showed that resilience is about bouncing back to previous functioning rather than flourishing beyond previous functioning (Smith et al., 2008; Windle & Bennett, 2011); it could be those carers who need to adapt least who are most resilient. Staying positive has several beneficial functions: positive cognitions buffer against sources of burden (Zauszniewski, Bekhet and Suresky, 2009); enjoyment in the role reduces burden and depression (Pinquart & Sörensen, 2003); and sharing a joke can maintain companionship (Murray et al., 1999), reciprocity (Voelkl, 1998) and the care recipient’s sense of identity (Hellström, Nolan & Lundh, 2005). Downward comparison with those that are ‘worse off’ may be an important way of increasing self-efficacy and the carer’s confidence in how well they are doing (Farran et al., 2004). The acquisition of knowledge supports existing dimensions of resilience, such as favouring challenge and garnering control (O’Rourke et al., 2010). Other facilitating factors emerged at a community level, and included friendships with common experience and social participation. Specifically, we showed that friends provide a source of mutual experience and shared understanding for dementia carers. Good quality social relationships may be those that have been reinforced through shared experience (Farran et al., 2004).

Hindering factors emerged at individual and community levels of the ecological framework. We showed that individual factors such as a negative outlook, and focusing on aspects that have become lost or irreparably changed, are frequently associated with non-resilient participants. At a community level, we showed that the perceived or actual loss of friends can hinder resilience, and increase feelings such as isolation. This supports Gaugler et al. (2007), who characterised highly resilient dementia carers as more accepting of informal support. We found that some factors are only facilitating up until a point, after which they may become hindering. Our data gives examples of this from individual, community and societal levels; at an individual level, a sense of freedom and access to disposable income may be limited by the demands of dementia. This finding is unexpected and would not be predicted by the resilience framework, which might have predicted that a lack of material resources was instead a hindering factor. The fact that our participants did not raise lack of money as a negative issue is not to say that it is not a valid factor. No empirical research has looked directly at the role of material resources in facilitating resilience. At a community level, family support that is perceived as over-intensive may create feelings of overdependence. This is unexpected given that carers often prefer social relationships based on shared experience, and family members are likely to share more experience than friends (Farran et al., 2004). Pinquart and Sörensen (2000) suggest this may be because family are structurally determined and associated with negative social exchange surrounding the sick relative, whereas friends are selected and more synonymous with the ‘good old times’. At a societal level, respite care is valuable but some participants feel that they are not ready for it or are unaware of its availability. This emphasises that access to resilience resources is not always sufficient; carers must wish to use them. This supports Bennett’s (2010) view that the time has to be right to achieve resilience.

The current study contributes much that is new. First, by focusing exclusively on spousal care, we provide a novel perspective through which to examine resilience. Qualitative interviews examine the individual experience of dementia care; however, we were also able to identify a number of community and societal resources. Unexpectedly, few societal resources emerged from our analysis. The resilience framework suggests that social policy, employment, neighbourhood and economy issues might emerge more but they did not. This may be due to the nature of our interview; we asked questions that focused on psychological and interpersonal aspects of the caregiving experience, encouraging participants to talk mainly about their affective and behavioural reactions. Wild, Wiles and Allen (2011) found that social resources emerged prominently when participants were asked about community, household and neighbourhood issues. Despite this we uncovered some important societal factors which seem to strongly facilitate resilience in our participants. By operationalising resilience we were able to identify who is resilient and who is not, which may aid the promotion of resilience through formal and informal intervention. A key limitation of the current study is that the majority of the sample is recruited from dementia support groups which may represent a resilient sub-group of participants such that the findings cannot be generalised to other non-resilient carers. However, six out of twenty of our participants were recruited from outside support groups and not all those participants recruited from support groups are resilient. Furthermore, it is difficult to recruit those carers who are not known to services and so emphasis should be placed on extending our findings to them. Another limitation is that the notion of drawing on assets and resources, and the classification system used, may be too simplistic. We showed that some factors are only facilitating up until a point, after which they may become hindering. We also found that some resilient participants draw on factors that hinder resilience and some non-resilient participants draw on factors that facilitate resilience. This suggests that resilience is more multidimensional than we thought. Further discussion of these issues go beyond the scope of this paper. Our study emphasises the continued need to integrate resilience within an ecological framework (Windle & Bennett, 2011), using different methods of research and analysis

In conclusion, a resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one’s former self. Resilient carers have access to and use services such as respite care and may actively engage with innovative schemes that aim to ‘give back’ to others in similar situations. Resilient carers are knowledgeable and well-supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better. In doing so carers may be more encouraged to pursue the positive aspects of caring which go on to buffer the effect of burden on resilience. Resilient carers can be encouraged to share their knowledge and expertise with those who are not resilient. The ideal forum for this to happen is the support group setting; a societal resource, within which individual assets and community level resources can be facilitated. Formal services could also step in to help potentially at risk individuals, such as those who are not resilient and/or those without knowledgeable peers.Our findings emerge on individual, community and societal levels which suggests that resilience is a multidimensional construct and supports the continued need to examine resilience from an ecological perspective.

*References*

Alzheimer’s Society (2012). *Dementia 2012 report: an executive summary.* Retrieved from http://alzheimers.org.uk/site/scripts/download\_info.php?fileID=1390.

Bennett, K. M. (2005). Social engagement as a predictor of objective and subjective health. *European Journal of Ageing, 2,* 48-55.

Bennett, K. M. (2010). How to achieve resilience as an older widower: turning points or gradual change? *Ageing and Society, 30*(3), 369-382.

Bennett, K. M., Hughes, G. M. & Smith, P. T. (2005). Psychological response to later life widowhood: coping and the effects of gender. *Omega, 51*(1), 33-52.

Bennett, K. M., Vidal-Hall, S. (2000). Narratives of death: a qualitative study of widowhood in later life. *Ageing and Society, 20,* 413-428.

Bonanno, G. A. (2004). Loss, trauma and human resilience: have we underestimated the human capacity to thrive after extremely adverse events? *American Psychologist, 59*(1), 20-28.

Calasanti, T. & King, N. (2007). Taking ‘women’s work’ ‘like a man’: husbands’ experiences of care work. *Gerontologist, 47*(4), 516-527.

Charmaz, K. (1995). Grounded theory. In Smith, J. A., Harré, R. & van Langenhove, L. (eds), *Rethinking Methods in Psychology.* Sage, London, 27-49.

Farran, C. J., Loukissa, D., Perraud, S., & Paun, O. (2004). Alzheimer’s disease caregiving information and skills. Part II: family caregiver issues and concerns. *Research in Nursing & Health, 27*(1), 40-51.

Gaugler, J. E., Davey, A., Pearlin, L. I. & Zarit, S. (2000). Modelling caregiver adaptation over time: the longitudinal impact of behavior problems. *Psychology and Aging, 15,* 437-450.

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journals of Gerontology, 62*(1), 38-44.

Greenfield, E. A. (2009). Felt obligation to help others as a protective factor against losses in psychological well-being following functional decline in middle and later life. *Journal of Gerontology: Psychological Sciences, 64*(6), 723-732.

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress appraisal, coping and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*, 323-330.

Hellström, I., Nolan, M., & Lundh, U. (2005). ‘We do things together’: a case study of ‘couplehood’ in dementia. *Dementia, 4*(1), 7-22.

Ingersoll-Dayton, B., Morgan, D., & Antonucci, T. (1997). The effects of positive and negative social exchanges on aging adults. *Journal of Gerontology: Social Sciences, 52,* 190-199.

Lévesque, L., Ducharme, F., & Lachance, L. (1999). Is there a difference between family caregiving of institutionalized elders with or without dementia? *Western Journal of Nursing Research, 21*(4), 472-497.

Murray, J., Schneider, J., Banerjee, S., & Mann, A. (1999). Eurocare: a cross-national study of co-resident spouse carers for people with Alzheimer’s disease: II. A qualitative analysis of the experience of caregiving. *International Journal of Geriatric Psychiatry, 14*(8), 662-667.

Nolan, M., Grant, G., & Keady, J. (1996). *Understanding Family Care.* Buckingham: Open University Press.

Office for National Statistics (2001). *Living in Britain 2001.* Stationery Office, London.

O’Rourke, N., Kupferschmidt, A. L., Claxton, A., Smith, J. Z., Chappell, N., & Beattie, B. L. (2010). Psychological resilience predicts depressive symptoms among spouses of persons with Alzheimer’s disease over time. *Ageing and Mental Health, 14*(8), 984-993.

Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *Journal of Gerontology: Psychological Sciences, 58*(2), 112-128.

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *Journals of Gerontology. Series B (Psychological Sciences and Social Sciences), 62,* 126-137.

Potgieter, J. C., Heyns, P. M., & Lens, W. (2012). The time perspective of the Alzheimer caregiver. *Dementia, 11*(4), 453-471.

Projecting Older People Population Information System. (2007). *Dementia: people aged 65 and over predicted to have dementia, by age and gender, projected to 2030.* Retrieved April 16, 2012, from http://www.poppi.org.uk/index.php?pageNo=334&PHPSESSID=9o5229nkluptpjvop04bh5j440&sc=1&loc=8640&np=1.

Seddon, D., Robinson, C. A., Tommis, Y., Woods, B., Perry, J., & Russell, I. (2009). A study of the carer’s strategy (2000): Supporting carers in Wales. *British Journal of Social Work, 40*(5), 1470-1487.

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In Smith, J. A., Harré, R. & van Langenhove, L. (eds), *Rethinking Methods in Psychology.* Sage, London, 9-26.

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P. & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. *International Journal of Behavioural Medicine, 15*(3), 194-200.

Ungar, M. (2011). *The Social Ecology of Resilience.* New York: Springer.

Voelkl, J. E. (1998). The shared activities of older adults with dementia and their caregivers. *Therapeutic Recreation Journal, 32*(3), 231-239.

Wiles, J. L., Wild, K., Kerse, N. & Allen, R. E. S. (2012). Resilience from the point of view of older people: ‘There’s still life beyond a funny knee.’ *Social Science & Medicine,* *74*(3), 416-424.

Wild, K., Wiles, J. L. & Allen, R. E. S. (2011). Resilience: thoughts on the value of the concept for critical gerontology. *Ageing & Society,* 33, 137-158.

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21,* 252-169.

Windle, G., & Bennett, K. M. (2011). Resilience and caring relationships. In M. Ungar (Eds.), *The Social Ecology of Resilience* (pp. 219-232). New York: Springer.

Windle, G., Woods, B. & Markland, D. A. (2010). Living with ill-health in older age: the role of the resilient personality. *Journal of Happiness Studies, 11*, 763-777.

Wuest, J. (2000). Re-patterning care: woman’s proactive management of family caregiving demands. *Healthcare for Woman International, 21*(5), 393-411.

Zauszniewski, J. A., Bekhet, A. K., & Suresky, M. J. (2009). Effects on resilience of women family caregivers of adults with serious mental illness: the role of positive cognitions. *Archives of Psychiatric Nursing, 23*(6), 412-422.

Table 1: Demographic details and resilience classification of carers.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Carers (N=20) | Age (years) | Marriage duration (years) | Care duration (years) | Resilient/Not resilient |
| Mrs W. | 62 | 28 | 3 | Not resilient |
| Mrs C. | 68 | 48 | 9 | Resilient |
| Mrs Wi. | 69 | 51 | 4 | Not resilient |
| Mrs F. | 71 | 51 | 3 | Not resilient |
| Mrs L.\* | 73 | 53 | 10 | Resilient |
| Mr G. | 81 | 52 | 5 | Resilient |
| Mrs G.\*\* | 82 | 49 | 5 | Not resilient |
| Mrs Go. | 69 | 40 | 5 | Resilient |
| Mrs O. | 77 | 59 | 2 | Not resilient |
| Mrs S. | 86 | 61 | 6 | Not resilient |
| Mr Go. | 74 | 52 | 10 | Resilient |
| Mr Wh. | 71 | 50 | 10 | Resilient |
| Mr H. | 81 | 53 | 5 | Not resilient |
| Mrs P. | 75 | 49 | 4 | Not resilient |
| Mr N. | 71 | 41 | 7 | Resilient |
| Mr Gr.\* | 88 | 56 | 9 | Not resilient |
| Mrs H. | 89 | 58 | 7 | Not resilient |
| Mrs La. | 83 | 55 | 2.5 | Not resilient |
| Mr Ha. | 80 | 52 | 3 | Resilient |
| Mrs Cl. | 69 | 49 | 3 | Not resilient |

Key: \*Widowed \*\*Institutionalised

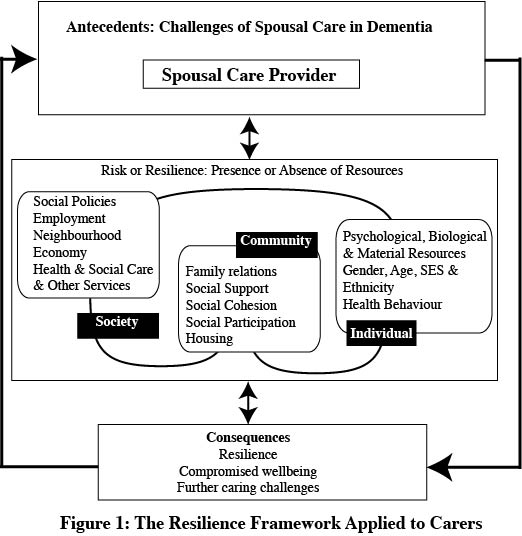


Figure 1: The Resilience Framework applied to carers (Windle & Bennett, 2011).